

Consent Policy Design Group

Meeting Minutes

MEETING DATE	MEETING TIME	Location
April 9, 2019	1:00PM – 2:00PM	Join Zoom Meeting: https://zoom.us/j/269726549 Dial: +1 646 876 9923 US Meeting ID: 269 726 549

DESIGN GROUP MEMBERS					
Stacy Beck, RN, BSN		Susan Israel, MD	x	Nic Scibelli, MSW	x
Pat Checko, DrPH		Rob Rioux, MA	x		
Carrie Gray, MSIA	x	Rachel Rudnick, JD	x		
SUPPORTING LEADERSHIP					
Allan Hackney, OHS	x	Chris Robinson, CedarBridge	x	Tim Pletcher, Velatura	x
Carol Robinson, CedarBridge	x	Ross Martin, CedarBridge	x	Lisa Moon, Velatura	
Michael Matthews, CedarBridge	x	Sheetal Shah, CedarBridge	x	Sabina Sitaru, HIE Entity	x

Minutes			
	Topic	Responsible Party	Time
1.	Welcome and Overview	Michael Matthews	1:00 PM
	<p>Allan Hackney welcomed and thanked the Design Group members. Allan said that this is the sixth Design Group that has been sponsored by the Advisory Council and facilitated by CedarBridge Group and he has always been amazed by the talent and knowledge represented by the participants. Allan thanked the group on behalf of the Advisory Council and explained that this group will shape the direction, policies, and approaches that Connecticut will take when the statewide health information exchange is launched. It is vitally important that we are able to gather people's perspectives on this topic.</p> <p>Michael Matthews welcomed the Design Group members and provided an overview of the agenda. Michael introduced members of the CedarBridge support team.</p>		
2.	Public Comment	Attendees	1:02 PM
	There was no public comment.		
3.	Introductions and Participant Opening Comments	Design Group Members	1:05 PM
	<p>Michael Matthews asked the Design Group members to give their background and to explain their perspectives on consent and why they are interested in participating on this Design Group. Michael recognized that Stacy Beck and Pat Checko were not able to join this call but will provide their input during the next meeting.</p> <p>Carrie Gray: Carrie is the Director of Information Security at University of Connecticut (UConn) Health. She has been involved with information security for the past 20 years. She is interested in finding out what role she needs to play in this particular Design Group. She's not clear where HIPAA Security crosses over into the Design Group. She wants to see how she can provide feedback as the meetings progress.</p> <p>Susan Israel: Susan's background is in psychiatry and for the last several years has been interested in patient privacy rights, specifically privacy vs. confidentiality. Susan said that in 2003, the federal government took away the patient's right of consent for treatment, payment, and healthcare operations (TPO). She advocates for patients to control who sees their data and that it's not automatically taken for TPO purposes and distributed. Susan wants to know more about data segmentation, and whether or not this means the data stays in the provider's EHR and how comprehensive this will be.</p>		

Rob Rioux: Rob is the Chief Operating Officer at Community Health Association of Connecticut (CHCACT). CHCACT is the trade group for 16 community health centers across the state. Previously, he had worked at a community health center for 6 years which was a very positive experience for him. This group is much more of a learning opportunity for him. Health centers are breaking new ground on information exchange and his organization is helping them build tools and systems to facilitate this exchange. He wants to learn and contribute to this conversation and ensure that we are keeping patients at the center of everything we do.

Rachel Rudnick: She is Associate Vice President and Chief Privacy Officer for both UConn and UConn Health. She has been with UConn for 13 years and took over responsibilities for UConn Health about a year ago in a new Joint Office of Privacy Protection and Management. They are taking a new approach to privacy management and compliance at UConn. Her interest in this group is similar to Carrie Gray's. She is also working on other projects where UConn is collaborating with the Office of Health Strategy (OHS). She is looking at this from a Privacy Officer's perspective in terms of the need to protect individual rights and how to best manage that protection as an institution and balance the rights and responsibilities.

Nic Scibelli: Nic is a licensed clinical social worker and Chief Information Officer at the Wheeler Clinic, which is a stand-alone FQHC and large provider of behavioral health services, including mental health and substance abuse. Wheeler Clinic lives and breathes consent management and it is a key part for how they do business. At the same time, information exchange is becoming more critical to them and their ability to properly treat their patients. This is an area that he has a great amount of operational experience in and a great interest in helping figure out the best way to work this into the health information exchange.

4.	Overview of Consent Design Group Workplan	Michael Matthews	1:15 PM
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Michael Matthews provided an overview of the Design Group's workplan. There are 8 total meetings currently scheduled, and each has a specific meeting objective. The Design Group's work will be completed by July 23, 2019. Meetings 1 and 2 will cover level-setting and ensure everyone has the same context and background. Meetings 3 and 4 will be facilitated by OHS's consulting partners at Velatura. These meetings will take a specific look at TPO-based consent policy, specifically related to the initial use cases for the statewide HIE. After the first 4 meetings, an interim set of recommendation will be developed and validated. Meetings 5 and 6 will discuss use cases A and B related to consent policy. There are a huge number of possible use cases for consent, we will be trying to structure a process for consent policy monitoring, management, and development to account for the dynamic environment. Meetings 7 and 8 will focus on the development and validation of final recommendations for delivery to the Health IT Advisory Council.

Next, Michael provided an overview of the role of the Consent Policy Design Group. The group will analyze existing policies from other states, review relevant policies and legislation, and discuss issues and barriers to information exchange. The group will also develop and recommend an initial approach to patient consent in support of the first wave of recommended HIE use cases under HIPAA TPO and will recommend an ongoing process and structure for evolving the consent model for supporting the HIE Entity and future use cases.

Next, Michael provided an overview of the Design Group process. The Design Group will report out to the Health IT Advisory Council, who will consider and endorse the recommendations. The recommendations will inform the policy framework for the soon-to-be-formed HIE entity.

Michael provided an overview of several level-setting discussion points. Michael highlighted one point in particular; that the patient must be the "north star" in all of our deliberations. In addition, the policies need to be developed to promote flexibility and allow for adaptations over time. These level-setting points will be revisited throughout the Design Group process.

Michael explained that consent is more than "opt-in vs. opt-out" as this is an outdated paradigm. The world of information exchange has become more complex in recent years. Michael provided a list of potential HIE use cases that could be addressed in the near future. Michael said that one size does not fit all for consent. Connecticut is in the process of developing and implementing a "network-of-networks" model. Provider

	organizations and other networks will be connecting to the statewide HIE and all entities will need to agree to the rules of the road and align with the overall trust framework.		
5.	Review of Federal and State Regulatory Landscape	Ross Martin	1:25 PM
	<p>Ross Martin is working with the CedarBridge team to support this Consent Policy Design Group. Ross provided an overview of his background and experience.</p> <p>Ross explained that real and meaningful consent requires policy, technology, and patient engagement. The high-level policy discussions discussed data liquidity. The EHRs are not really capable of segmenting more sensitive data. When you think about how patients or caregivers are engaged, their ability to understand their options for how to manage their data is limited by the complexity of this topic.</p> <p>Ross explained that as the group establishes its recommendations, they will need to balance a number of very important proposed federal rules and regulations that are emerging. Ross explained that there are currently four initiatives / proposed rules emerging at the federal level: (1) Trusted Exchange Framework and Common Agreement (TEFCA); (2) HIPAA Request for Information (RFI); CMS notice of proposed rulemaking; and (4) ONC notice of proposed rulemaking. Ross said that after reading these rules, there are some primary themes that are emerging:</p> <ul style="list-style-type: none"> • Less: specific functionality requirements within the EHR • More: core interoperability and data flow capabilities • Heavy push towards standards-based application programming interfaces (APIs), such as HL7 FHIR®, to make interoperability simple and faster to implement. • No information blocking – all actors must not act in ways that impede data flow (with exceptions) <p>Ross said that a very important phrase in these proposed rules is “without special effort.” This means that the APIs need to be standardized, transparent, and pro-competitive. Ross provided an overview of TEFCA. The 21st Century Cures Act required ONC to “develop or support a trusted exchange framework, including a common agreement among health information networks (HINs) nationally.” The draft document was released on January 5, 2018, which was followed by a public comment period. The final framework has not yet been released. Ross presented a diagram that outlines how the Trusted Exchange Framework will work, including an explanation of the Recognized Coordinating Entity (RCE) and Qualified HINs. Ross said we need to be thoughtful about these emerging rules and be forward-thinking and flexible.</p> <p>Next, Ross provided an overview of the HIPAA RFI, which provides some insight into the federal government’s thoughts in terms of updating or modifying this piece of legislation. One of the main questions asked was related to the importance of informing patients of their rights through the Notice of Privacy Practices. Also, the RFI asks if caregivers, or appropriate family members, should be given some “break the glass” access to information in the case of an emergency. Many comments have already been submitted.</p> <p>Next Ross provided an overview of the CMS and ONC notices of proposed rulemaking (NPRM). Both NPRMs look at aspects of the same issues, including interoperability, information blocking, how EHRs will be certified and managed, and patient matching. Patient matching is very important to HIEs. The proposed rules also discuss APIs, how providers and payers are involved in care coordination, and provider directories. There is also discussion on the dual-eligible population, modernizing the National Plan and Provider Enumeration System (NPPES), information blocking, and more (as outlined on the slides). One thing to note is the emergence of a new acronym, EHI (electronic health information). This is an opportunity to distinguish explicitly between health information in an electronic form vs information in other formats, such as paper.</p> <p>Ross explained that Design Group members received one-page summaries of all four of these emerging federal initiatives to provide additional context and detail. Ross said that next week, the group will spend more time on data segmentation for privacy and consent to share.</p>		

6.	Open Discussion	Design Group Members	1:50 PM
	Lauri Johnson asked who prepared these slides. Ross Martin indicated that CedarBridge Group developed the slides. Lauri Johnson thinks that the slides are very well done.		
7.	Wrap up and Meeting Adjournment	Allan Hackney	2:55 PM
	Ross explained that at the next meeting, the team will go deeper on consent management and what is happening in surrounding states. They can also start to think about how they can talk about the initial use case for TPO issues. Michael Matthews thanked Ross Martin and the group. He also indicated that there will be more opportunity for group discussion in future meetings.		

Upcoming Meeting Schedule: April 23, 2019; May 7, 2019, May 21, 2019

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